

Lewy Body Life

Season 1, Episode 3: Is the Unpredictability of LBD Making You Anxious?

Music starts

Welcome to Lewy Body Life.

Lewy Body Life helps care partners, family and friends understand and navigate the often complex and unpredictable Lewy Body Dementia journey.

Here real people with real experience and real insight share essential information for caring and coping. We hope our podcast series will help you realize that you're not alone and that there are strategies and resources that can aid you in your LBD journey.

Now let's go to your co-hosts Ann Brucciani Lyon, Paula Rice Bieber and Linda Olsen Engel.

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Ann: Hello and welcome, I'm Ann Brucciani Lyon.

Paula: I'm Paula Rice Bieber.

Linda: And I'm Linda Olsen Engel.

Ann: We are glad you could join us for today's episode — Is the Unpredictability of LBD Making You Anxious?

Paula: Before we get started with our third episode, we'd like to thank the families in the Minnesota LBD Caregiver Support Group and the Twin Cities Support Group for Persons with Lewy Body Dementia.

Linda: Definitely. We really appreciate all the feedback, encouragement and financial assistance of this podcast series — from the support groups — and from our family members and friends who have listened to our episodes and helped craft them into what they are now.

Ann: Our listeners should also know that we are not medical, legal or tax professionals and the information shared here is not intended to replace seeking the appropriate professional advice for your specific situation.

Paula: We're here to help raise awareness and understanding, and hope that the information we share will help guide you to the resources you need.

Linda: And, most importantly, we want you to know you're not alone. Being a Lewy Body caregiver can become isolating and feel really lonely at times.

Paula: Sometimes you really are in a situation where it is just you. But there are others who have gone through these same circumstances. We want you to know that we are here to help.

Linda: That's right.

Paula: In our first episode, we discussed what Lewy Body Dementia is and how it is diagnosed. In our second episode, we took a closer look at the types of changes that happen early on in the Lewy Body Dementia journey.

Linda: So now let's get back to today's topic and our big question: Is the Unpredictability of LBD Making You Anxious?

Paula: I think everyone is going to answer **yes** to that question, Linda!

Linda: I agree, Paula.

Ann: And you know, that anxiety can feel overwhelming no matter what sort of caregiving situation you find yourself in, and no matter how much help you get.

Paula: Yes, and as we begin delving into today's topic, we want to acknowledge that there are many perspectives on whether to care for a loved one at home or move them to a care residence. And that everyone has differing personal beliefs and values about this.

Linda: A person may even feel conflicted within themselves on what to do, changing their preferences from one day to the next. I experienced this while caring for my late husband.

Paula: This internal struggle is very common.

Ann: It weighs heavily on most people.

Paula: Yes, it's a hard decision to make. But regardless of whether you care for your loved one at home or if they are in a care residence, you remain a caregiver.

Linda: Exactly, And caring for someone with LBD is uniquely stressful for a variety of reasons.

Paula: That's right. And you need support to deal with that stress — as well as with the tasks of caregiving — in order to sustain yourself.

Linda: You're so right about that Paula!

Ann: We will talk later in this episode about what to consider when making a decision about what the appropriate care environment is.

Paula: We are going to first talk about the reasons you may be feeling anxious and tools and strategies that can help you cope with stress no matter what your situation is.

Linda: And I think we should also talk about how to care for yourself as well.

Ann: Yes. And before we start, let's take a moment to invite our listeners to take a couple of deep calming breaths.

Linda: Right now?

Ann: Yes, right now! Breathe in, breathe out. Breathe in, breathe out. Breathe in, breathe out. And another one — Breathe in, breathe out.

Pause

Paula: Oh, that felt good!

Ann: It did, didn't it? Doing this type of breathing is one of the ways that you can take a mini-break and soothe yourself so that you can look at things from a fresh perspective.

Paula: And now let's take an honest look at what causes LBD caregivers to have so much anxiety and some ways we can cope with the stress inherent in being a caregiver.

Linda: Yeah, let's get started.

Ann: As Paula was just saying, when a caregiver is dealing with the unpredictability of LBD, caregiving without support is difficult to sustain.

Paula: I hear you, Ann. The ordinary tasks of caregiving in and of themselves are extremely wearing. Add in the unpredictable nature of LBD — you are often facing new symptoms or an unexpected decline — and people just want to throw in the towel some days.

Linda: That's for sure! At times, the LBD rollercoaster can even cause care partners to feel sick to their stomachs, have trouble sleeping or maintaining concentration. It's like we are waiting for that other shoe to drop.

Paula: And sooner or later it does. That's why it's so important for people to build an emotional support network, and create a toolbox of coping strategies that they can use.

Linda: And to ask for help.

Paula: We can't emphasize enough how important asking for help is. It's not going to go away, it's not going to get better,

Linda: Yes, for most people, LBD is a marathon, it's not a sprint. So asking for the help you need is critical to your well-being and to the well-being of the person for whom you are caring. It is a struggle. Don't suffer in silence.

Ann: It's also really important that you're open with people about what you're going through. The only way we are going to learn from one another, understand how to be helpful *and* to build awareness of this disease is to be honest with ourselves and with others.

Linda: So true, Ann. Frequently when I've checked in on carepartners to see how they're doing and offer assistance, I've found that there's a hesitancy on their part to accept help, even in cases where their exhaustion is so very evident.

Ann: Yes, and the reasons why differ from person to person. Regardless, it's important to know that it is okay to ask for help and to be very specific about what you need.

Paula: Because people who would like to help may not know what sort of help the caregiver really needs!

Linda: Exactly. I once offered to sit with a Lewy husband so his carepartner wife could get out of the house. She replied that what she'd really like to do is get out and have lunch with me! Then we discussed utilizing the "Home Instead" care agency so she could do that.

Paula: Like you said before, Linda, we too often have a tendency to think we should be able to do everything all by ourselves, and we should always put up a brave face and not ask for help.

Ann: But sharing what you are going through is really important.

Linda: A recent Facebook post was written by a woman who held everything inside during her husband's LBD journey because, as a caregiver, she didn't want to burden anyone else.

Ann: I remember that story!

Paula: I do too. After her husband passed, she had a really difficult time because her children had no idea how hard the journey had been on her or why she was now having problems adjusting.

Linda: That's right, by the time she finally was ready to share some of her caregiving experiences her friends and family had a difficult time believing her!

Ann: The takeaway was that she regretted that she had not been more open and had not asked for help because she now felt even more isolated and lonely being disbelieved than she did when she was suffering in silence.

Linda: Her children had never experienced with their Dad what she had gone through with him as a spouse and caregiver.

Paula: She must've felt so alone keeping everything to herself. She was trying to protect them, but that meant that there was no one to support her!

Linda: This is why I like and recommend support groups. If a caregiver isn't ready to share with friends or family, or finds that they don't understand or sometimes don't even believe one's experiences, a support group is where people can find others who are on the same journey.

Ann: And Paula, as the person who leads two support groups — one for caregivers of people with LBD and one for people with LBD and their care partners, I think you'd agree that finding a support group is an important part of building an emotional support infrastructure and can help lessen caregiver anxiety.

Paula: You are absolutely right. Being with a supportive group of people who are going through the same sort of things you are, really can lessen the anxiety of being a caregiver.

Linda: For me, being in a support group was a big positive turning point in my search for help. It affirmed that I was not alone and not the only one burning out. Others were also getting angry at their loved ones and then feeling badly about giving in to that inevitable anger that erupts.

Ann: Plus, a support group helps you take care of you.

Paula: When you fear you are going to crash and burn, when you fear you can't do it any longer, it can create extraordinary anxiety — joining a support group is one of the ways that you can put your own proverbial oxygen mask on first, take a deep breath or two, like we did at the beginning of this episode, and then feel able to go on with caregiving.

Linda: That's a great analogy Paula. Just like when you're on an airplane and the flight attendant goes over the safety instructions, passengers are advised to put on their oxygen mask first before helping those around them. This is how they can ensure that they are able to help others.

Ann: That's so true!

Paula: And speaking of helping others, a support group isn't just about getting help for yourself. It is so empowering when you are able to help someone else in the support group deal with an issue that you've experienced.

Linda: You're right, Paula, yes, we don't feel so helpless and anxious when we are able to help someone else!

Ann: And it's important for our listeners to know that it's not just finding a support group, it's finding a support group that has the right focus and the right mix of people to meet their needs.

Linda: Absolutely. Some of our listeners may be searching for a group that focuses on research and information. Others may want to focus more on shared experiences and personal stories. Some want a mix of both.

Paula: Yes, and If you try a group and it's not the right fit, don't give up on support groups and think that they don't work for you.

Linda: Try another group. If you can't find a good fit in your area, search for one that meets virtually, many groups meet via Zoom now after Covid.

Ann: So, support groups are one way to help you deal with stressful situations and can help lessen anxiety.

Paula: That's right, Ann. But let's go back and talk some more about what causes LBD caregivers to have so much anxiety.

Ann: Paula, you'd mentioned the unpredictability of LBD as one of the major causes of stress.

Paula: Yes, I did.

Ann: That reminds me of something I heard Donald Rumsfeld say while he was serving as Secretary of Defense. It was something that has stuck with me ever since because it holds true in nearly every facet of life.

Linda: This sounds interesting. Would you share this?

Ann: He said, 'There are known knowns. These are things we know that we know.'

Paula: That makes sense.

Ann: Yep, that one is pretty straightforward. He also said there are known unknowns. That is to say, there are things that we know we don't know.

Linda: Cool, I'm tracking so far.

Ann: And finally he said there are also unknown unknowns. Those are the things we don't know that we don't know. And I think it's so important to recognize that there are so many known unknowns and so many unknown unknowns when you are an LBD caregiver."

Linda: Wow, Ann! I love the concept of unknown unknowns with this!

Ann: Thanks, Linda.

Linda: Let's talk about the effect of these unknown unknowns.

Ann: Yes, they are certainly a big factor in why LBD creates so much anxiety for the caregiver and for the person living with the diagnosis.

Paula: I think the biggest "unknown unknown" when you start on the LBD journey is that there aren't distinctive stages to this disease.

Linda: I agree. We expect to be given information about how things will progress, what we will face because with most diseases there are identifiable steps.

Paula: It is a shock to find out that doctors can't really predict what is going to happen next or how fast the disease is going to progress.

Ann: Something I want to mention that can be very confusing for caregivers, is that if you google "Stages of LBD" there are websites that list stages. And I think this is really misleading.

Paula: I'd like to give some history about that. Medical professionals refer to LBD as having early, mid and late stages. But the progression of dementia, especially Alzheimer's, is often described as having seven stages — three early stages, a mid stage, then three stages of severe decline.

Ann: Right.

Paula: And so you'll sometimes see these stages adapted to describe Lewy body. Some LBD caregivers found it useful to fit the various symptoms into particular stages.

Linda: But in reality LBD is basically a rollercoaster.

Paula: That's right. You can have severe symptoms at the very beginning and then have stretches of moderate impairment years into the disease. There is such a variety in the type of issues that occur. That's unlike Alzheimer's.

Ann: Yes, reading about the so-called stages of LBD can help a person get a general idea of what to expect, but it doesn't help you deal with the unpredictable aspects of the disease, or tell you how fast, or in what order things will progress.

Paula: The unpredictability of LBD is discussed frequently in our support group meetings.

Linda: I can see where the unknown unknowns of LBD combined with an uncertain prognosis can create many challenges and cause a lot of anxiety.

Ann: Well, that makes sense, right? I recently read an article that included information from the National Center for Biotechnology Information. That group found that the uncertainty about a possible future threat disrupts our ability to avoid or cope with its negative impact, and thus results in anxiety.

Linda: Having ridden that roller coaster, I wholeheartedly agree.

Ann: Yes, and when you are a caregiver to someone with LBD, the unpredictability of the disease and how it will affect the person you are caring for can also feel very threatening at times.

Paula: There is such tremendous uncertainty with LBD it can lead a caregiver to feeling fearful or threatened — either directly because of acts of aggression toward them or indirectly because you're never certain how an individual with LBD is going to respond in any given situation, in any given moment.

Linda: Yes, one might wonder "Is he going to have a forgetting episode? — Will there be an outburst? — Is he or she going to tinker with something, forget a step, put us at risk of an accident or injury? Will our loved one become unexpectedly hostile toward us?" Or, Paula, like with your dad, is he going to act out a delusion?

Paula: Yes, and those delusions were so real to my dad! I never knew if it was going to be a minor distraction for him or a big deal — like insisting on going to a business he thought he owned or stating that he needed to write out paychecks to employees he didn't have.

Ann: And you know, because the appearance of symptoms and behaviors is so uncertain — so random — so absolutely unexpected, LBD caregivers are always in a reactive mode. Sometimes a shift away from normal into an LBD episode happens so quickly that we don't immediately realize we are dealing with a loved one's distorted reality.

Paula: Most definitely and this is what puts us on edge all the time. It's hard to let go of that feeling of constant alertness.

Linda: Oh gosh, I sure remember that feeling! Afterwards, it seems like I'm experiencing post traumatic stress syndrome!

Paula: Many of my support group members have commented about feeling that way as well — even when they no longer are caring for their person the effect of being on duty 24/7 remains.

Ann: You know, I'm thinking this might be a good time to bring up the concept of "ambiguous loss" which is another stressful emotional response that's common for caregivers.

Linda: That isn't as much about anxiety, though, as it is about grief. But it is something people feel without really understanding why.

Ann: I think you are right, Linda. Paula, this may be a new term for some of our listeners. and you're really good with explaining this — can you take a moment and explain what ambiguous loss is?

Paula: Sure. Ambiguous loss occurs when your loved one is still physically present but is no longer filling the same roles that they once did.

Ann: Because they are no longer capable of doing them.

Paula: That's right. You can no longer expect them to mentally or emotionally respond to you in the same ways they did before. You are grieving the loss of their abilities and the role they used to fulfill in your life.

Linda: That reminds me of moments in my past, and the emotional shifts that took place, when I went from feeling like my husband was an equal partner to knowing that I had to take over the bulk of responsibilities in our relationship — including the ones he'd previously filled.

Ann: Can you share an example?

Linda: Let me think for a moment.

Paula: You probably have a lot to choose from.

Linda: I do. The one that's coming to mind right now is about the way we managed tasks at our cabin.

Ann: Tell us about it.

Linda: Well, I would do the inside maintenance and he handled everything outside. Gradually I had to join him with all his dock and yard work tasks because he no longer had the capacity to do those correctly or consistently, or at all. It was devastating.

Ann: I'm sure it was. These moments of realization can feel overwhelming — even threatening. In part, because you're losing the valued contributions of your partner and, at the same time, having to take over or learn how to do things that, let's be honest, you may not want to do. In part, because you may want to keep the lifestyle you have — for example,

trips to the cabin — and the reality created by the unpredictability of the disease may cause you to question if going anywhere at all is too risky.

Linda: Yes, that's exactly what happens.

Ann: And it doesn't matter if you and your spouse have filled traditional or non-traditional roles. For some, their husband may have done the cooking or their wife may have done the bills. And you have to learn these skills in addition to the ones that you already contribute.

Linda: Exactly! The emotionally supportive role they had in your life also changes. They can no longer "have your back" or help you resolve problems, or discuss things in the same in-depth manner as you once previously did.

Paula: Yes, it is a tremendously difficult transition. And you know, the person with LBD feels this grief as well. They know that they aren't able to do the same things they could before.

Ann: And you combine the things we've been talking about — stress about dealing with fluctuating symptoms, uncertainty about what will happen next and the sense of grief for what has been lost — this can cause so much stress that it can be dangerous to a caregiver's health and well-being.

Paula: That's why it's so important for caregivers to learn coping techniques and to know when and how to ask for help. They can't just keep going under that amount of emotional stress.

Linda: Looking back, I found that living in the present moment helped me cope. For example, I learned to compartmentalize issues by telling myself, "Don't worry about this now. Worry about it later." Then I would focus on the most immediate task at hand.

Paula: That's a great recommendation, Linda.

Linda: Thanks

Ann: I once heard, "Worry is a price you pay on a debt you may not owe." When I start to worry, especially about things that might happen or could happen, I think of this quote and it helps me set aside my concern until it actually becomes a reality. Often it doesn't.

Linda: It's also helpful to learn to separate the person you are supporting from the disease itself.

Paula: Some caregivers personify the disease as "Lewy" which enables them to vent against the disease, not their person! They are able to say to themselves "I hate Lewy!" instead of focusing their anger on their loved one.

Linda: Some people in the support group shared that when their loved one is acting up, they say, “Oh, sure looks like Lewy is with us today!”

Paula: Developing that detachment is part of the process of facing the fact that the person you are caring for isn’t able to fully control their responses to events and emotions anymore.

Ann: But that’s easier said than done. Especially because there are times that a conversation you’re having suddenly shifts from being normal to not normal. Like I mentioned earlier, the shift occurs so quickly that by the time you realize what’s happening — that “Lewy” is present — you’ve already dug yourself into a hole.

Linda: For sure!

Paula: That’s when taking a moment to step into a different room or outside for a few minutes can help create a healthy space between you, so that you can reset.

Linda: It’s a very unpredictable journey. That’s why we need to be emotionally kind to ourselves and forgive ourselves for the mistakes we make, and for — in retrospect — not knowing all the things we wished we had known at the time.

Paula: Yes, sometimes we need to be better friends to ourselves!

Ann: Agree.

Linda: I’m going to switch gears here a bit. We hear a lot about using the practice of mindfulness to help with stress.

Ann: We do.

Linda: Those mindfulness techniques can help caregivers take a sort of mini-break, like we did at the beginning of this episode, with the breathing exercise.

Paula: Taking a few deep breaths and focusing on the process of breathing really can calm your mind. Doing this for just a couple minutes can make a huge difference!

Ann: And when you feel stressed out, pay attention to your body — lower your shoulders, relax your jaw and loosen your hands.

Paula: And maybe take a big yawn — that helps too.

Linda: So does paying attention to what is immediately around you, such as the light coming in from outside, or the sounds that surround you. Doing this without really thinking or talking to yourself, lowers that emotional tension.

Ann: There are a lot of good apps that can help provide meditational guidance, some, like Aura, that have 3-minute routines for people who have limited time.

Paula: That's a great recommendation! Another thing I've found some people really enjoy is taking a little mental vacation by imagining a place they'd like to be, like lying in a hammock on a sunny day, or hearing the waves lap against the shore, or creating an imaginary garden.

Ann: I love this idea!

Linda: Right? Paula, thanks for mentioning this.

Paula: One of the Facebook LBD Support Groups I am involved with started choosing a weekly fantasy vacation destination. We pick a place and then talk a bit about it. We imagine what we would do there, what we would eat or drink. We talk about whether we would sit around a campfire, lay on the beach or hike in the mountains. It's a great way to take a mental break from talking about all the issues we are facing.

Ann: Those Facebook support groups can be really great — there are so many different ones now and they have members from all over the world.

Linda: It's fantastic, really. So — even if you are up in the middle of the night — you can probably post and get a quick response from someone.

Ann: I know these things might sound trite or insignificant against the burden of caregiving, but they really can help reduce anxiety if you make a habit of creating an inner space for yourself where you can feel at peace, even if it's just for a few moments.

Linda: Creating inner space actually sounds wonderful, Ann. You might also try things like journaling or coloring in adult coloring books, playing sudoku or Wordle — that's hot now.

Paula: Or doing virtual jigsaw puzzles like I love to do!

Ann: My go-to is exercise. You know, any activity you can put down and pick up later can help keep you from spinning your wheels and feeling like all you are doing is caregiving or worrying about caregiving.

Linda: I'm with you on that — downhill skiing was my escape. A break in the fresh air doing a sport that I loved always helped me reset. Now I'd like to go back to something we mentioned earlier.

Ann: What are you thinking about, Linda?

Linda: We agreed how important it is to take time for yourself. Consider asking a friend or relative if they could come over for a couple hours so that you can get a break from caregiving,

Paula: Or at least have someone with you for a while, even if you can't leave!

Linda: Precisely. And I'd like to suggest that our listeners find out if there is someone in their faith community or a senior home health care service provider, or an elderly sitters service that can help.

Ann: The three of us have talked about the benefits of doing this. Structure breaks at scheduled times so that you can look forward to them, plan for that time and enjoy them. Establish a routine so that there is something you can count on — some predictability — in the midst of chaos.

Paula: That is so important. You may feel like you are doing well and think you don't need a break. But it's still important to take breaks for yourself even if you don't feel that it is necessary.

Linda: Yeah, you have to find ways to create some predictability in your rollercoaster world. Scheduling things that you can look forward to is so important and can help keep your stress level down.

Paula: The hard part is doing those breaks without feeling guilty about taking time for yourself. But remember, this is part of putting your own oxygen mask on first, before you can help someone else with their needs. You need that air in order to do your best when you are back in the trenches!

Ann: Absolutely. You need to recharge and refuel or you won't have the resources you need later to do the job that is required of you.

Linda: Oh, I like that! Another important thing to keep in mind here is to focus on what you *can* change, and not so much on what you have lost.

Ann: That's not always easy, especially when you see your peers out doing the things you thought you and your loved one would be doing — whether that's spending time traveling, attending cultural events, volunteering in your community, spending time with family and friends whatever it may be — but an LBD diagnosis and caregiver responsibilities are now hindering those pursuits.

Paula: And it is natural to feel resentful about this. As caregivers we find ourselves no longer able to do things that we regard as basic to who we are as persons, an important part of what our lives are about.

Linda: For sure. So if you have activities you enjoy, and you can't change that your spouse isn't able to do them with you, look for other ways to do them.

Paula: So even if you can't do the fun things you used to do, find ways you can make those activities part of your life. Join an online group that discusses that activity and share your experiences and expertise, maybe help others with their plans to pursue those activities.

Linda: There are so many ways to be involved, even if you have very little time for yourself. An upside to the recent pandemic is that so many things are now available virtually through Zoom or online platforms. You can participate remotely if you have a day where you just can't get physically away.

Paula: Senior centers, family service organizations, and community education programs offer life enrichment programs too, about all sorts of interests and topics.

Ann: Again, this is another way you can help alleviate stress and anxiety. I'd like to go back to something related to our discussion about ways caregivers can give themselves a break. Look into day activity programs for your loved one. They give you more time for yourself while providing social opportunities for the person you are caring for.

Paula: And listeners, there are also excellent caregiver coaching programs that can help you to learn how to take things in stride and not feel so overwhelmed.

Linda: Paula, can you share a few examples?

Paula: Well, the Powerful Tools for Caregivers program comes to mind. It can help you find ways to actually "take care of yourself" — that phrase that we have been talking about so much. Google the terms "dementia caregiver coaching" or "Powerful Tools for Caregivers" to find how to access these resources.

Ann: Finding a therapist can also be very beneficial. A therapist can help you address feelings like guilt, anger, frustration — especially if you tend to be more private in nature and aren't comfortable discussing your reactions with the people in your social circle, or need more one-on-one time than a support group can offer.

Paula: Yes there are therapists who specialize in working with dementia caregivers and the unique challenges that they face.

Ann: Let's pause here for a moment and briefly recap our key points. We talked about how the anxiety caregivers feel is normal and commonplace. The stress of caregiving, the unpredictability of LBD and how ambiguous loss all play a role in causing that anxiety. We discussed some ways to take mini-breaks when you feel anxious, and the importance of making time for yourself in order to take real breaks. Joining a support group can be a big help, as is seeking guidance from caregiver coaches or therapists who specialize in dementia caregiving issues. They can work with you individually to help you cope and help alleviate anxiety. There are now a lot of options and opportunities for caregivers.

Linda: Good recap Ann! You know this is a long episode and we've got a ways to go yet. If people feel they need a break, now would be a good time to do that.

You know, we were speaking about therapy. The nature of LBD has some unusual qualities that may make a caregiver begin to feel like *they* are going crazy — that *they* can't get a grip on what is going on with their loved one.

Ann: That's for sure.

Paula: Yes. That's because the behavior of a person with LBD can replicate gas lighting.

Ann: If you haven't heard of gaslighting, it refers to a specific type of manipulation where the manipulator is trying to get someone else — or a group of people — to question their own reality, memory or perceptions. But unlike a manipulator who is intentionally trying to undermine someone, an individual with LBD is doing it unintentionally.

Paula: Yes, that's a really important difference. They are not deliberately trying to convince you that your perceptions are false, even though they know otherwise. The things that they say and the actions that they take are happening as the result of a degenerative brain disease that changes their perception of reality. What they accuse you of or think is going on, is actually real to them.

Ann: It can start out small, for example, your loved one may accuse you of having misplaced or stolen an item when you haven't. Or they may tell you that a conversation or an argument that you'd had together never happened.

Linda: And their delusions increase as their brain tells them stories attempting to explain things that they don't remember or that go along with an emotion that they are feeling, like fear or anger.

Ann: But the problem is that even more-or-less insignificant instances can be unnerving and cause you to question your own judgment about reality over time and this can cause anxiety.

Paula: Especially since due to the fluctuating cognition that is a hallmark of LBD, the person you are caring for may not even remember having accused you of something or giving you such a far-fetched explanation.

Linda: They may be so matter of fact about what they think happened that you begin to doubt yourself. Other people may buy into what they say.

Ann: That's because they don't know the person with LBD as well as you do. You know them well enough to know when a behavior is out of character or to know they have forgotten

something they used to know, or how to do something they did well but others may not know them well enough to recognize that.

Paula: Yes, others may not think much of a situation or may doubt your version of what is happening. You end up feeling judged and disregarded. This can upset and distract you to the point where you are not able to navigate the situation in a clear minded, focused way that allows you to make good decisions.

Linda: Wow, I sure experienced that.

Ann: Paula, you know Linda was caring for a spouse with LBD. You were caring for a parent. Did you experience this sort of thing also?

Paula: It wasn't like that for me. My siblings and I were pretty much on the same page throughout Dad's illness. When Dad would visit with friends or relatives, they also caught on pretty quickly that Dad was having delusions. Maybe because his delusions were so obviously not true. He didn't own airplanes or hotels. He was able to fool people who didn't know him, though.

Ann: What about your Mom?

Paula: You know, my Mom may have experienced this at earlier stages of his disease. I know she had problems getting his doctor to take her concerns seriously.

Ann: That brings back to me the importance of something we talked about before — taking notes, because that can help alleviate anxiety also, and give you something you can look back on and remind yourself that an incident did happen the way you remembered it. And Linda, you did a great job with note taking. When do you think these disconnects with your husband started to occur?

Linda: Well, Ann, looking back, it started about 20 years into our marriage, which was 30 years before my husband's death. Sometimes when we were around his family members, he would uncharacteristically start criticizing me, picking on me verbally, giving me glaring looks and creating uncomfortable interactions between me and others. Now I've come to realize those situations were probably Lewy first showing its presence.

Ann: That's really shocking to think about, Linda. The first signs started so early — 30 years before he passed. I think that will give all of our listeners pause and cause them to start thinking about when they actually started noticing personality or behavioral changes that were out of character.

Linda: Yes, as we mentioned in Episode 2, these types of changes can be one of the very early warning symptoms.

Ann: A recent Alzheimer's Association Report said that people may begin displaying symptoms of Alzheimer's for 18 years before a diagnosis occurs. And this may be true for LBD as well. As our knowledge and diagnostic tools improve, it won't surprise me if future studies show — like your journal — an even longer timeline.

Paula: We are learning more and more about these neurodegenerative diseases all the time.

Linda: Yep, we are. And in my situation, these sorts of behaviors increased over the years into more delusional and paranoid accusations. Eventually he accused me of having affairs, which is a very common delusion with LBD

Ann: Paula mentioned this isn't intentional but that doesn't mean that it isn't taking an emotional, physical and psychological toll on the caregiver.

Linda: That's for sure! At the time therapy helped me remain sane. But having a therapist who understood LBD — that would have been even more helpful.

Ann: So Linda, in that situation what actions did you take to help reduce your anxiety?

Linda: Like Paula said earlier, the counselors helped me to understand the importance of putting my own oxygen mask on first.

Paula: What did that look like for you?

Linda: Well, that's where support group participation really became a lifesaver. I had to "sneak" to the meetings because if my husband had known, he would have been furious. At probably the second meeting I clearly recall kind faces, nodding heads, and the voice of one person who expressed for me what became a nugget of gold: "If you're concerned, there's probably something to be concerned about."

Ann: That's true. You've got to trust your gut instinct. Others may try to justify the behavior as normal, even when — as I said earlier — you know it's not normal for that person.

Linda: Exactly.

Paula: What are some of the other ways you helped yourself stay sane?

Linda: Early on, when he could still be left alone, I began attending social events without him, even though it made him angrier.

Ann: Going to events without him may have been uncomfortable for you and it obviously agitated him. But your not maintaining a healthy connection to other people would have been worse for both of you.

Linda: Absolutely, I needed to do that. Then, at least fifteen years before he passed, I took a part time job at a ski resort in order to have a life away from what had become a daily roller coaster.

Ann: Smart, smart choice. How did that work out for you?

Linda: Well, some of my husband's friends began to believe him when he said I was having an affair. But, I knew I was taking care of me so I would be able to handle the heavy lifting that was coming up ahead. Since then, I've heard and read about many LBD people accusing their care partners of having affairs. That's an example of the paranoia aspect of the disease.

Paula: The delusions can be paranoid in nature and handling accusations can be very difficult. We'll be talking more about that in a future episode.

Ann: Well, if we know one thing, it's that Life with Lewy sure is complex. And I think it's now time to talk about the fact that not everyone is able — because of these pressures — to keep their loved one at home throughout the course of this disease for a host of different reasons.

Linda: Yes, that's a huge issue and reminds me of how important it is for individual carepartners to know their personal limits for caregiving.

Paula: It is.

Linda: Mmm, hmm. One of the best pieces of advice that I was given while caring for my husband was to think about the tasks I was currently doing, visualize tasks I would need to do in the future, and decide at what point I would no longer be comfortable — or able — to care for my husband at home.

Paula: That's a great recommendation, Linda. And I think it's something that is very difficult for a lot of people to do. But it's important to define what your limits are and then to honor them.

Ann: You know, we are told that the number one consideration in this decision is safety. You have to determine when it's no longer safe for your loved one, or for you, to do the caregiving at home.

Linda: Yes, exactly! For me personally though, even before safety became an issue, (and I'm not uncomfortable sharing this truth) it was incontinence. I've never had the constitution of a nurse. Oh, how I've long admired and appreciated people who are nurses! So, performing the mental exercise of dealing with "incontinence" helped me accept that I wouldn't be able to do that task.

Recognizing that personal limitation, I was better able to accept the inevitable and take the necessary next step when it was time to do so. Interestingly, incontinence and the possibility

of having a dangerous fall occurred for us simultaneously, which helped me accept the need to protect him with placement in a safer setting.

Ann: Tough stuff to think about. And thanks for sharing such a personal example, Linda.

Linda: You're welcome. It's a perfect one — I mentioned that falling came the same time incontinence occurred. A dear friend who was visiting at our home (she's one of those marvelous nurses I respect so much) witnessed this and said, "Forget the incontinence, you have multiple dwelling levels in your home. You either need to change the structure here so that you aren't dealing with falls, or you will have to move him."

Paula: Yes, Everyone needs to identify what their personal tipping point will be. Maybe it's when your loved one is experiencing delusions or hallucinations and you can no longer respond effectively to them because their reactions are so extreme and distressing.

Ann: Or maybe it's when caregiving is so disruptive to your ability to get a good night's sleep that you aren't functioning well during the day.

Linda: Those are more great examples! Given all the possibilities, as part of your self care, you need to be realistic about what you can and cannot do or what you're willing and not willing to do. And then you need to have a plan in place for when you reach your tipping point.

Ann: For my grandma, it was about physical strength. When she was no longer strong enough to help my grandfather in and out of the bathtub, she knew that it was time for him to go to a senior residence.

Paula: Let's talk about how hard it can be to be honest with yourself about what your capacity for caregiving truly is.

Ann: It can be really hard. Some people are natural caregivers, others are not. That's not a shortcoming, it's simply a difference in how one individual and another may be hardwired.

Linda: Excellent point. It doesn't matter what anyone else in your situation is choosing to do. What matters is what works best for you and the person for whom you're caring.

Ann: There was a gentleman who had placed his wife in a senior care residence and he was feeling really guilty about it. He had made a commitment to visit her every day. Soon after, when he would show up, his wife was so engaged with the activities available to her, she told him she was too busy to visit. It was such a relief for him and brought such joy to her.

Linda: Yes, people can really do well and have needs met in a care residence that they aren't having met at home. That's another thing to keep in mind when feeling anxious about whether or not a move is the best option.

Paula: We brought up this topic because whether to care at home or not is a concern that does cause a lot of anxiety.

Linda: We hope that we gave you some ways to think about that decision that will make it less stressful. But it is a broad topic and we'll talk more about it in another episode devoted to that subject.

Ann: I think it's about time that we wrap up this episode. We hope you've found our discussion about the causes of caregiver anxiety and ways to cope with stress helpful.

Paula: In our next episode, Episode 4, we'll talk about effective ways to respond to the more challenging LBD symptoms like delusions, hallucinations and agitation and other situations when the person you are caring for is in distress.

Ann: Knowing how to respond to those situations can certainly help with anxiety and stress!

Linda: And on the other hand, being able to respond in a calm and thoughtful manner makes the techniques that we'll talk about more effective.

Paula: So this episode and our next episode really go hand-in-hand.

Tune in to our fourth episode: "Responding to Challenging Situations."

Linda: In the meantime, we wish you strength and courage as you travel the LBD journey.

Ann: We do. And, if you think the content we covered today may be of benefit to someone else, please share this episode!

Paula: Thanks for joining us. For more information, visit our website at www.lewybodylife.com.